



Living with

LAMBERT-EATON MYASTHENIC SYNDROME

You have received this leaflet as you have been diagnosed with Lambert-Eaton myasthenic syndrome (LEMS). This leaflet will give you and your family some more information about LEMS, what you can expect and the medical treatments that can be used.

The information in this leaflet is provided to support your understanding of LEMS but is always secondary to the advice of your doctor. If you have any questions or concerns, please make sure to discuss them with your doctor.

What is LEMS?

LEMS is a rare autoimmune disorder that stops nerves from communicating properly with the muscles. It occurs when antibodies (that normally help you) attack the ends of the nerves and stop them from releasing acetylcholine, a messenger substance that transmits impulses from your nerves to your muscles.



Types of LEMS

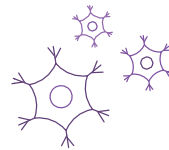
There are two types of LEMS:



Cancer-associated LEMS

(also called paraneoplastic LEMS)

About half of people with LEMS have cancer, usually a smoking-related cancer called small-cell lung cancer. This type of LEMS generally starts later in life (around 60 years of age) and is more common in men than in women. It is thought to occur when the body makes antibodies against the cancer that then mistakenly attack nerve cells.



Non-cancer-associated LEMS

(also called non-paraneoplastic LEMS)

In other people, LEMS is not associated with cancer. This type of LEMS occurs in people of all ages (although it is more common in older people) and generally affects men and women equally. Doctors are not sure what triggers the immune system to attack the nerves in this form of LEMS.



What are the symptoms of LEMS?

LEMS can affect many different parts of your body. The symptoms of LEMS usually begin slowly, starting with general fatigue, muscle weakness (particularly in your legs) and dry mouth. You may have difficulty with some everyday actions like getting up from sitting or climbing stairs. The muscle weakness may get worse over time and usually spreads downwards from your hips and thighs to your feet, and upwards towards your head.

Sometimes (but not as often) LEMS can also affect the muscles that help you talk, chew and swallow, and cause problems with regular bodily functions like going to the toilet.

How is LEMS diagnosed?

Your doctor diagnosed LEMS based on your symptoms and by looking for specific changes in electrophysiological tests, which measure how well nerve signals reach your muscles. A blood test may have also been performed to check for the antibodies that can cause LEMS.

Your doctor may have sent you for a CT scan to check for lung cancer, especially if you smoke or have previously smoked. LEMS can be an early warning of cancer.

How is LEMS treated?

There is currently no cure for LEMS, but your doctor may recommend treatment to help relieve the symptoms.

The specific treatment depends on the cause of your disease. If a cancer is found, the first step is to treat the cancer. If your LEMS is not associated with a cancer, or if treatment of the cancer does not help your symptoms, management may include medical treatment and/or supportive care.

Your doctor will decide, along with you, on the most appropriate treatment.



Medical treatment

Medical treatment for LEMS usually works in one of two ways:

1. Improve nerve transmission

Aminopyridines: *Increase the amount of acetylcholine available to transmit impulses from the nerves to the muscles*

Cholinesterase inhibitors: *Increase the transmission of nerve impulses by preventing the breakdown of acetylcholine*

2. Reduce the activity of the immune system

Immunoglobulin treatment: *Reduces the amount of antibodies in the blood*

Plasma exchange: *Filters the blood to remove the antibodies*

Steroids and other immunosuppressants: *Medications that suppress the immune system*

Supportive care

Your doctor may recommend other ways to help relieve your symptoms, improve your comfort or prevent complications, including:

- Lifestyle modifications, such as stopping smoking, following a healthy diet and taking exercise
 - Treatment to prevent conditions such as deep vein thrombosis and peptic ulcers
 - Avoidance of medications that make your muscle weakness worse
 - Extra monitoring for infections
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What happens next?

Although LEMS may be with you for many years, treatments are improving all the time and can help to bring your LEMS under good control.

Your doctor may arrange for you to have regular appointments with a neuromuscular specialist. As LEMS can be associated with cancer, your doctor may also recommend regular screening for cancer if no tumour is found when you are first diagnosed with LEMS. Depending on your symptoms and treatment plan, other examinations may also be recommended.

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